

# #strongerforlonger

Help us share our model of therapy to change the lives of thousands of people with muscular dystrophy in the US and UK.

## Why build a tool-kit?

**Most funding for MD goes into medical research, to change the lives of people in the future. But what about people who are losing muscle function today?**

We want to change access to therapies. Using our tried and tested therapy model, our toolkit will give people with MD the resources, support and inspiration they need to start their own therapy clinics.

**The tool-kit will include everything from therapy techniques to tips on tech innovation for patient management systems. We want to freely share everything we've learned, to make it possible for others to launch successful clinics quickly and cost-effectively.**

The first tool is a short film showing our therapy programme. This will be shared widely across the MD community in the US and UK, in order to spark the collective action needed to address access to therapy.

**If our toolkit enabled just 4 new clinics, at least 1,000 more people with MD could be staying stronger for longer within three years.**

**Imagine if we enabled 10 new clinics, or even 100? That could mean upwards of 25,000 people staying stronger for longer, transforming the landscape of therapy access completely.**



**Muscular Dystrophy  
Support Centre**  
*inspiring independence*

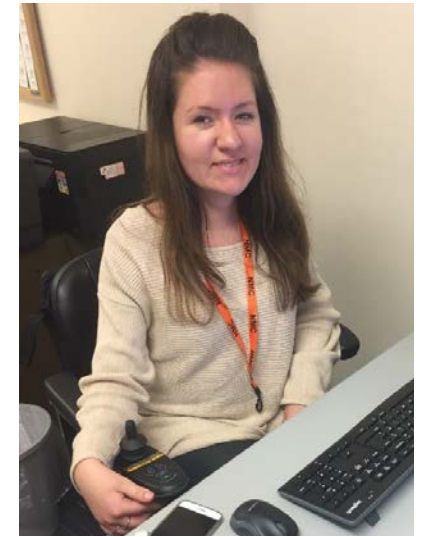
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## TAO'S STORY

"My name is Tao. I started coming to the Muscular Dystrophy Support Centre aged 22. I have Mini Core Myopathy, a rare form of muscular dystrophy, and my mobility had really deteriorated. I have physiotherapy once a fortnight, hydrotherapy weekly and occasionally, osteopathy.

Therapy makes such a difference. I used to be in a lot of pain but I hardly have any pain any more. I am more flexible, and my core strength and balance have improved. Now I have a much better understanding of my condition. I have grown in confidence and rely less on my friends and family now.



At 24, buying an electric wheelchair felt a bit like I was "giving in" and going backwards. But Ulrike, my physiotherapist, helped me see things in a different light; saying "it conserves my energy, that I am not giving in, I am using it to enable me to do more and go forward, without restrictions." This helped me so much. I had a hoist fitted to my car so I could take my wheelchair out alone. For the first time in months, I was independent again. Now, at 25, I'm starting a career I have always wanted, and I am happy and excited about the future."

## What is our therapy model?

**Specialised** – our therapists have knowledge and experience of muscular dystrophy and related neuromuscular conditions. Treatment isn't limited to a series of exercises. It may include work on strengthening the core, hands-on muscle manipulation, or use of specialist exercise equipment.

**On-going** – muscular dystrophy doesn't go away after 6 weeks, so we don't discharge after 6 weeks. In fact we don't discharge at all, so service users can rely on us to help them manage their condition long-term.

**Preventative** – When someone begins to lose muscle function in one area, without meaning to they may compensate by over-using another muscle, which can start a downward spiral. Early intervention means spotting these progressions quickly, focussing on efficient muscle use and retaining the best possible overall condition. With early intervention, many people even see an improvement in their baseline function level after a few months' therapy. It follows that subsequent decline is lessened accordingly.

**Multi-disciplinary** – our service includes physiotherapy, osteopathy, hydrotherapy and a range of complementary therapies. Following an initial assessment with a physiotherapist, the service user and the therapist make a personalised treatment plan based on the service user's own goals.